

## Supplementary file 4: Summary of analysis of Phase 3 cognitive de-brief interviews

<b>ANAL -</b> <b>7 participants: 2 male, 5 female. Age range 38 – 73</b>	<b>GYNAE</b> <b>7 participants: all female. Age range 35 - 75</b>	<b>HEAD AND NECK</b> <b>3 participants: 2 male, 1 female. Aged range 61 - 66</b>
<p><i>HPV is a virus that is passed from one person to another during sex or physical intimacy. It affects both men and women, and it is so common that most of us get it at some point in our lives.</i></p>	<p><i>HPV is a virus that is passed from one person to another during sex or physical intimacy. It affects both men and women, and it is so common that most of us get it at some point in our lives.</i></p>	<p><i>HPV is a virus that is passed from one person to another during sex or physical intimacy. It affects both men and women, and it is so common that most of us get it at some point in our lives.</i></p>
<p>All understood the message; it was news to three of them and one was shocked to realise the association with cancer.            “I knew that it was passed sexually, but not that it was anything to do with cancer... makes me feel worse... makes me think how I got it.”</p> <p>One woman, a trained nurse, found the messages easy to understand and appreciated that medical words were not used. She had had a very negative experience.            ‘It’s a shame the doctors didn’t speak to me like that. That’s a nice way to put it. I was made to feel dirty, forced into having an HIV test....’</p>	<p>One was interviewed with her daughter and was clearly very shocked.            “She was struggling to understand how this could have happened, and couldn’t really get beyond that thought.”</p> <p>However, all the participants understood the message. One patients commented:            “I didn’t know it was men as well”.</p>	<p>Both participants found the message clear and understood it.            .....“Very well put together... de-stigmatising”.</p>
<p><i>HPV causes nearly all anal cancers. It also causes cervical cancer and some cancers of the vulva, vagina, penis and head and neck.</i></p> <p>Participants found this a clear message, although they were mostly unaware of this.</p>	<p><i>HPV causes all cervical cancer, nearly half of vulval and two thirds of vaginal cancers. It can also cause some cancers of the anus, penis and head and neck.</i></p> <p>Participants understood this message, and only one commented:            ‘It’s clear but I didn’t think it caused <i>all</i> cervical cancers – they told me it caused most ....’</p>	<p><i>HPV causes about half of oropharyngeal cancers (which can involve the tonsils, tongue base and soft palate). It also causes cervical cancer and some cancers of the vulva, vagina, anus and penis.</i></p> <p>Both participants understood the message. One commented:            “That’s all I need to know. The fact that HPV causes half prompts the question, what causes the other half?...”</p>
<p><i>HPV is usually cleared by the body’s own defences but, in a few people, it stays in the cells of the affected area for months or years. Then it sometimes causes the cells to change, and that may lead to cancer.</i></p> <p>All found the message clear, with one commenting that they didn’t know that and it could be a bit frightening.            “Frightens you a bit.... It can be there and you don’t know anything about it.</p>	<p><i>HPV is usually cleared by the body’s own defences but, in a few people, it stays in the cells of the affected area for months or years. Then it sometimes causes the cells to change, and that may lead to cancer.</i></p> <p>All participants found the message clear, although one asked:            “...whether they could find HPV when they do cervical smears. [She had abnormal smears a few years ago, treated by laser].”</p>	<p><i>HPV is usually cleared by the body’s own defences but, in a few people, it stays in the cells of the affected area for several years. Then it sometimes causes the cells to change, and that may lead to cancer.</i></p> <p>The two participants understood the message but one commented that he did not like the word “few”:            “...don’t like the idea of being only a few... it seems less normal, more scary... “some [people]” would be less alarming... it could be any of us.”</p>

<p><i>Even if HPV causes cells to change, it can take another 10 years or more for cancer to develop.</i></p> <p>All found the message clear, though some said that they did not know this.</p>	<p><i>Even if HPV causes cells to change, it can take another 10 years or more for cancer to develop.</i></p> <p>Five of the six participants agreed the message was clear and they understood it. One remarked:  “...frightening to think you’ve had it so long and don’t know.”</p> <p>The sixth participant was having difficulty understanding how she came to have this cancer:  “... but she just hadn’t reckoned that she could have encountered the virus 40 years ago.”</p>	<p><i>Even if HPV causes cells to change, it can take another 10 years or more for cancer to develop.</i></p> <p>The participants found the message straightforward and clear.</p>
<p><i>Most people never know they had HPV because there usually aren’t any symptoms. It is hard to know when you got HPV or who you got it from.</i></p> <p>All participants said they found the message clear, or had no comment to make.</p> <p><i>HPV can be spread to the anal area by intimate skin-to-skin contact or anal sex.</i></p> <p>All participants understood this message.</p>	<p><i>Most people never know they had HPV because there aren’t usually any symptoms. It is hard to know when you got HPV or who you got it from.</i></p> <p>Participants all understood the message:  ‘I don’t suppose we’ll ever get to the bottom of it!’</p>	<p><i>Most people never know they had HPV because there aren’t any symptoms. There is no way of knowing when you got HPV or who you got it from.</i></p> <p>The participants understood the message.  “This reinforces number 4... That’s good... We’ve moved from self-image to assessing those around us.”</p> <p><i>HPV can be transmitted by oral sex as well as other forms of intimate contact.</i></p> <p>The participants understood this.  ‘This fits completely... I was always an enthusiastic cunnilinguist!... Glad to have it confirmed...demystifies it...’</p>
<p><i>It is easy for HPV to be transferred between the genital and anal area, especially in women.</i></p> <p>All participants understood:  “‘Yes, I could imagine that.”</p>		<p><i>There is some evidence that HPV may be transmitted by deep or ‘French’ kissing but not by sharing drinks or kissing on the cheek.</i></p> <p>The participants understood the message and found it reassuring that HPV couldn’t be passed casually.</p> <p><i>Head and neck cancers caused by HPV usually respond better to treatment than other types</i></p> <p>These two patients had already been told this by their consultant and had found it reassuring.</p>

<p><i>There is no treatment for HPV but there's now a vaccination to prevent it. It's best for young people to be vaccinated before they are sexually active.</i></p> <p>The participants understood the message. One commented that it referred to girls and not boys.</p>	<p><i>There is no treatment for HPV but there's now a vaccination to prevent it. Girls are vaccinated in the first year of high school.</i></p> <p>Participants had no problem understanding this message and some had been aware of the TV campaign; one commented that boys should be vaccinated as well.</p>	<p><i>There is no treatment for HPV infection but there's now a vaccination to prevent it. It's best for young people to be vaccinated before they are sexually active.</i></p> <p>The participants understood the message. One commented that they were pleased to hear it.</p> <p>“...good news... removes any residual feelings of guilt.”</p>
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### Frequently asked questions

#### *What does this mean for my relationship?*

Having HPV-related cancer doesn't mean you or your current partner have had sex with someone else. The virus was likely picked up many years ago and there is no need for shame or blame.

You and your partner will have already shared whatever infections you have and no changes in physical intimacy are needed.

#### *Am I or my partner at risk of getting another HPV-related cancer?*

You might be at a slightly higher risk, so you should report any symptoms to your doctor, but remember that these cancers are very rare.

#### *What about previous partners?*

There is no need to tell previous partners you have HPV. There is no test or treatment for it; most people clear the virus without treatment and without even knowing they had it.

Most participants found these messages easy to understand, although those currently not in a relationship did not see the relevance to them. Others found it reassuring because they still felt guilt, and two said they understood but would still be wondering who they got it from. Another was more relaxed:

“I just think I've probably got it so my partner's probably got it. Who gave it to who isn't worth worrying about...”

One patient who had had a bad experience commented:

“It's a shame the doctors didn't speak to me like that. That's a nice way to put it. I was made to feel dirty ....”

Participants understood the content of the message and several commented that they had asked this of their consultant or would have asked this question. Again, those currently not in a relationship found it irrelevant.

“That's good to know... I didn't know that... I'm being followed up”.

“... in view of her recent medical history (delaying going to the GP), she would in future report any symptoms immediately, and she seemed to understand that, although slightly raised, it was still a fairly low risk.”

One woman with head and neck cancer commented that she didn't think that cervical cancer was so rare.

All participants found this message clear. Some had thought about previous partners and others had not. One found this message reassuring and another felt that there is no blame and telling someone would just cause unnecessary stress. One said she had wondered who might have given her HPV:

“I've accused partners in my mind.'...'it's no bad reflection on me... I'm not guilty.”

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*Could I have done anything to prevent getting HPV?*

No, it is so common that nearly all adults get it and condoms would not have given you complete protection.

However, if you are a smoker, giving up smoking may help your recovery from cancer.

All understood the message and some commented on it being reassuring.

“That’s good to know.... I was made to feel so disgusting... that gives me peace of mind”.

Regarding the message about smoking, several found it not relevant to them as they were not smokers and one found it inappropriate:

.....”That’s putting pressure on somebody when they’ve just been diagnosed with something awful.”

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*Could I have got HPV any other way?*

This is very unlikely because HPV targets a type of cell found in the lining of parts of the body that only come into contact during sexual intimacy.

This was clearly understood although it was something some had wondered about.

“This stops anyone who is in denial.”

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